Siegel Rare Neuroimmune Association
Frequently Asked Questions about Acute Flaccid Myelitis (AFM) with Dr. Benjamin Greenberg

The audio of this FAQ is available at http://srna.ngo/a1g

**What is acute flaccid myelitis?**

Acute flaccid myelitis (AFM) is a paralyzing syndrome where the spinal cord gets damaged through one of multiple mechanisms. The damage occurs, leads to weakness of one or more limbs, and can affect breathing, arms, or legs. This syndrome, which has been seen for centuries, is making a reemergence within the United States over the last four years, with outbreaks of acute flaccid myelitis occurring in 2014, 2016, and 2018, causing paralysis in many children across the U.S.

**What causes acute flaccid myelitis?**

While it's been reported that there are several different viruses, toxins, and environmental agents that can lead to paralysis, in the current setting, most acute flaccid myelitis is likely due to a viral infection. While we haven't proven the virus in all cases, there is significant suspicion that a group of viruses known as enteroviruses, a cousin of the poliovirus, may be responsible for paralysis in a significant proportion, or even the majority of cases.

**Is acute flaccid myelitis contagious?**

We hear about the concerns of the contagiousness of acute flaccid myelitis all the time. The cause of acute flaccid myelitis is thought to be a virus that is extremely common and is the cause of a common cold amongst millions of children every year. Once somebody has the complication of that viral infection, specifically acute flaccid myelitis, we don't worry about the paralysis being passed from person to person. We feel that the paralysis is a rare event of a very common illness.

**Will someone who already has TM or another neuroimmune disorder be susceptible to AFM?**

We do not know which individuals are most susceptible to this rare complication of a very common illness. Acute flaccid myelitis appears to affect children and adults who have been perfectly healthy up until the time of their illness and paralysis. We have yet to see a population, including individuals with transverse myelitis or other autoimmune disorders of the central nervous system, be at a higher risk of AFM than others.

**What are the symptoms of acute flaccid myelitis?**

The most common initial symptom of acute flaccid myelitis is weakness in one or more limbs. As the condition progresses, it can cause paralysis in one or more limbs and can even affect a person's ability to breathe on their own, swallow on their own, or move the muscles of their face.

**What should a parent do when they suspect symptoms of acute flaccid myelitis?**

Whenever you have a concern about unexplained weakness in a child or loved one, that person should be evaluated by a healthcare professional. It's important to remember that there are a lot of causes of weakness that may not be acute flaccid myelitis, but prompt attention in a healthcare setting is needed to order tests and determine what the cause of weakness is.

**Where should treatment be sought?**

If you're ever worried about weakness that is unexplained, finding care with a healthcare provider is essential. Whether it's a pediatrician, a family practice office, an urgent care center, or an emergency room, having an evaluation to determine the cause is essential. If the symptoms are rapidly evolving or severe, that evaluation should occur in an emergency room.

**How do you diagnose acute flaccid myelitis?**

Whenever an individual presents with unexplained weakness, there are several tests that may be performed. The diagnosis of acute flaccid myelitis depends on clinical evaluation and on imaging obtained with an MRI machine. It is with that imaging that we can see patterns that are indicative of this condition.

**What are the treatments for acute flaccid myelitis?**

There are no proven therapies for acute flaccid myelitis. When admitted to a hospital, there are a variety of therapies that might be used to limit the damage to the spinal cord. These include intravenous immunoglobulin (IVIG), corticosteroids, and perhaps plasmapheresis (PLEX). While none of these treatments have been proven to change the course, individual patients should consult with their healthcare providers to determine which, if any, of these treatments would be indicated.

**Is there a relation between vaccinations and acute flaccid myelitis?**

To date, we have not been able to identify any link between vaccinations and the development of acute flaccid myelitis. The overwhelming majority of children who have been afflicted with this condition have not had a recent prior vaccination.

**Can acute flaccid myelitis be prevented?**

It's going to be critically important for us to determine the cause of acute flaccid myelitis so we can invest our resources to preventing outbreaks from happening in the future. In the meantime, we recommend that everybody take normal precautions in day-to-day life to prevent the transmission of the common cold. Hand-washing, sanitizer, and staying home when you or your child are sick helps prevent the spread of these types of infections.

**Is there a cure for acute flaccid myelitis?**

While there is no single treatment that can reverse the damage done by acute flaccid myelitis, we are seeing regular and sustained improvement in the children who have been affected. By taking part in a rigorous, systematic, and consistent physical therapy routine, we are seeing children regain function in the limbs that were once paralyzed.

**What is the relationship between EVD68 and acute flaccid myelitis?**

Most of the available scientific and epidemiologic evidence supports a relationship between enterovirus D68 and the outbreaks of acute flaccid myelitis that have been seen every other year in the United States since 2014. It is important to recognize that while this virus has not been isolated from the spinal fluid of the majority of cases with acute flaccid myelitis, there is ample biologic and epidemiologic data to link the virus with the condition. This is an area that needs further study, but at this time our best guess is that there's an association.